

Activity limitations and participation restrictions experienced by people with stroke in Musanze district in Rwanda

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Abstract

Background: Stroke is a major cause of long-term disability. Information regarding the limitations in activity and participation experienced by patients with stroke in a specific setting such as Musanze district in Rwanda would assist to develop the rehabilitation programmes that would take into consideration the functional challenges experienced post stroke.

Objective: To explore the activity limitations and participation restrictions experienced by people with stroke in Musanze district in Rwanda.

Methods: A qualitative phenomenological approach using in-depth face-to-face interviews with 10 participants was employed to gather the data that was analyzed using a qualitative thematic approach.

Results: The themes that arose as activity limitations included limitations in walking, self care, and domestic life activities. The themes related to participation restrictions as expressed by the participants were inability to return to previous occupation, decreased social interactions and inability to participate in religious activities.

Conclusion: The current study findings highlight the need for interventions to improve the functional status of stroke survivors.

Keywords: Stroke, activity limitations, participation restrictions, Musanze district, Rwanda

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Introduction

Stroke is a major cause of long-term disability. The outcome of stroke is as follows: one year after a stroke, about 30% of patients will be dead, and of the survivors, almost 40% will be dependent on others for their daily activities¹. Stroke has enormous emotional and socioeconomic consequences for patients, their families, and health services. Suffering a stroke challenges the assumptive identity, self-concept and role-capacity of the individual in the face of acquired deficits², and the period following discharge from hospital or from inpatient rehabilitation is the most challenging for almost all stroke patients³. This could be associated with a discharge without accurate assessment of the domestic environment, and the establishment of networks

to meet critical needs such as personal care and home modifications.

Understanding the challenges faced by those who have suffered a stroke is useful to identify the longer-term issues that primary care based services for stroke will need to address³. Studies which investigated the functional challenges experienced by stroke patients revealed that the main activity limitations experienced are inability to walk independently, dependence on bathing, eating and dressing, as well as in housework activities such as washing, cooking and cleaning^{4,5,6}. A study conducted in South Africa to determine the limitations in activity and participation experienced by community-dwelling stroke survivors discharged from an intensive inpatient rehabilitation programme at 6 months post stroke revealed that many participants were not independent in housework, food preparation, shopping, and public transport use⁷. Participation restrictions experienced are mainly the inability to return to the previous employment and social isolation². Most of the studies about people with stroke were conducted in developed countries, and were quantitative cross-sectional in design. According to Dowswell et al.⁸, quantitative measures may be more relevant to the concerns of researchers than to those of patients for whom the subjective, lived experience of stroke is likely to be of greater importance.

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Stroke patients at Ruhengeri hospital in Rwanda which serves Musanze district are admitted in the intensive care unit or the general medical wards of the internal medicine. The stroke care consists of medical and physiotherapy management only. The evidence accumulated however shows that effective stroke rehabilitation requires a multidisciplinary team and equipped stroke units⁹. The stroke patients discharged very early, and without follow-up rehabilitation services would likely experience a lot of functional limitations. In the absence of data on the potential burden of stroke, though, it is difficult to develop appropriate strategies to prevent stroke and its impact¹⁰. The researcher therefore decided to explore the limitations in activity and participation experienced by people with stroke in Musanze district in Rwanda.

Methods

Study setting

This study was conducted in Musanze district, in the Northern Province of Rwanda. The Musanze district is an area which is mainly rural, and where at least 91% of the population is engaged in agriculture¹¹. Most families (about 65%) live below the poverty line¹². In addition, many families have been destroyed by the 1994 genocide and the repetitive 1997-1998 wars in the region, leaving survivors with disabilities, widows and orphans. Musanze is the most mountainous district in Rwanda¹³, and has therefore difficult geographical access and transport. In Musanze district, there are neither outreach nor community-based rehabilitation services that are provided to stroke patients. These can only get the institution-based rehabilitation services as inpatients or outpatients.

Ethical considerations

Ethical clearance for the study was obtained from both the Research Committee at the University of the Western Cape in South Africa and the National Ethics Committee of Rwanda. Permission to conduct this study was obtained from the Mayor of Musanze district. Written informed consent was obtained from each guardian and participant. Participation in the study was voluntary. For purposes of anonymity and confidentiality, the quotations of data from the interviews were cited using the cryptogram P1 to P10 rather than the participants' names.

Study design

A qualitative phenomenological approach using in-depth interviews was employed to explore the activity

limitations and participation restrictions experienced by people with stroke in Musanze district from their own point of view.

Sample, inclusion and exclusion criteria

A sample of 10 persons with stroke living in Musanze district was purposively selected. The characteristics that were considered for the purposive selection were age, gender, and chronicity of stroke. These characteristics were found to be significantly related to positive or negative adjustment and development of self-concept post-stroke, and would contribute to a richer variation of the phenomena under study¹⁴. The chronicity of stroke was calculated as the difference between the date of data collection and the date of stroke onset. Patients who still needed assistance at least for one activity were included. On the other hand, it was necessary to recruit subjects who were able to articulate their experiences and feelings, and accordingly exclude individuals with communication or cognition problems. To obtain respondents with experiences related to stroke, individuals who had suffered other major diseases after the initial stroke were excluded (for example head injury, osteoarthritis and rheumatoid arthritis).

Data collection instrument

All interviews were conducted by the researcher using an interview guide developed on basis of the study objective, the literature, together with the researcher's experience. The participants were asked to tell the story of their stroke and the way it had affected their lives, beginning with the question: "Please tell me about any functional problems you are having since you got the stroke". There was then a series of guided probes to obtain an in-depth description of the limitations in activity and participation experienced.

Procedure for data collection

After permission was obtained from the necessary authorities, the in-depth interviews in Kinyarwanda were conducted with the 10 participants in their homes. To get 10 different participants, the patient who was contacted, and met the inclusion criteria, and agreed to participate in the study was recruited. All contacted subjects agreed to take part in the study and were willing and appreciative of the opportunity to relate their experiences. A convenient time and location was determined for the patient interviews which lasted on average 50 minutes. The rooms where the interviews were conducted were assessed before starting to ensure good quality recordings and without possible interruptions

and distractions. All interviews were audiotape-recorded, and the research assistant took field notes.

Data analysis

The tape-recorded interviews in Kinyarwanda were fully transcribed by the researcher. The transcriptions were then read and compared to audio tape recordings and field notes several times to verify accuracy¹⁵. A trained, multilingual translator translated the transcriptions into English and the researcher analyzed those transcriptions to identify the main patterns of responses and consistencies and divergences across participants¹⁶. Common concepts were coded as suggested by Miles and Huberman¹⁷, producing themes. Two weeks after the initial coding, another separate coding was done and the generated themes in the second and first coding were then compared. This led to further refinements, producing themes that were interpreted for the meaning of the content.

Trustworthiness of the data

To establish the trustworthiness of the qualitative data, Shenton¹⁸ suggested the concepts of credibility, confirmability, transferability and dependability as essential decisive factors for quality in qualitative research. To enhance the four criteria, different strategies were employed.

To enhance credibility of the data, the themes presented were illustrated with representative quotations from the transcribed texts¹⁹. To ensure confirmability of the data, a peer examination was used by the researcher discussing the research process and findings with colleagues and experts who have experience in qualitative research methods²⁰.

To enhance transferability of the data, a clear and distinct description of the study setting, the selection and characteristics of participants, data collection and process of analysis was used¹⁹. For this purpose, different characteristics that were considered to select informants included chronicity of stroke, gender, current age, and functional status (independent walking). To address the dependability of the data, the researcher has used a code-recode procedure during data analysis as suggested by Krefling²¹.

Results

Participants' characteristics

Five participants (50%) were females and five others

(50%) were males. The participants were aged between 24 and 79 years (mean age = 56.3 years, SD = 16.9 years). Half of the participants (50%) were married while three (30%) were widowed. The chronicity of stroke among the participants lies between 3 and 53 months (mean = 19 months, SD = 16.4 months). Eighty percent of the participants were involved in manual activities before the stroke, and the majority (60%) of them were cultivators before getting stroke. In Rwanda, agriculture is mainly for subsistence and is associated with low socioeconomic status.

Activity limitations

During the in-depth interviews, when participants were asked to describe the problems they were having since they got stroke, three themes related to activity limitations emerged: limitations in walking, limitations in self-care activities, and limitations in domestic life activities.

Limitations in walking

Limitations in walking were described by the majority of the participants interviewed, and varied from total loss of walking to a decrease in independent walking. As a strategy to cope with the mobility limitations, the participants revealed using a wheelchair or a stick to move around their homes or walk within the community.

Participants who were not able to walk expressed the dramatic negative effect of the stroke on walking as reflected in the following quotes:

"Since I became sick, I have never been able to walk and I always use a wheelchair to go somewhere" (P2).

"... I have a problem of not being able to walk. To reach somewhere, they (caregivers) lift me in their arms" (P5).

Some participants revealed that although they were able to walk, their capacity to walk independently had been reduced as quoted below:

"... I feel sad that I cannot walk as before and I am always at home. You see...when I am walking it is like I am walking using one leg and I am pulling the other leg...When I walk out of the house I use a stick, but I can't go beyond that road" (P3).

"... I walk very slowly ... I am no longer able to walk for a long distance. When I am walking even with a stick, I become tired in a short time" (P10).

Various participants revealed that physical environments in Musanze district was contributing to the limitations in walking as one of the participants said: *"... I cannot use my wheelchair out of the house because there are many stones outside there"* (P9).

Limitations in self-care activities

All the participants frequently raised dependence in self-care activities such as bathing, eating, going to toilet, and dressing. Participants expressed the need for assistance to carry out the self-care activities as quoted below:

"... I cannot feed myself without assistance ... Oh! I cannot even bath myself ... (P1)".

"...I cannot dress by myself. It is difficult to put on the belt or to close the buttons...my wife helps me" (P7).

The participants were psychologically affected by the issues around limitations in self-care activities. Some participants felt that it was shamefully to ask somebody to assist them in so basic daily activities. For example, a participant said:

"It is very sad to ask someone to bring me to the toilet. It is very shameful for me" (P1).

Many respondents were uncomfortable with their dependence in self-care and did not wish to burden their relatives, friends or volunteers, and this was a source of being psychologically affected in a way that the participants wondered why they did not die instead of living and burdening others. For instance, the participants expressed:

"... I cannot do anything for myself. You see, now it is my daughter-in-law who is feeding me, washing me and dressing me. ... She is newly married with my son and now rather than working for their new family; she is always assisting me ... What they did for me is enough. I wish that I should go back to my home and wait my death" (some tears came out of the eyes) (P5).

"... I feel like being a burden to my family because I am being assisted in everything ... Better I should have died" (P8).

Limitations in domestic life activities

The participants did not only have problems with walking and self-care activities. They also displayed problems with domestic life activities such as cooking, washing clothes and cleaning the house. While some participants felt that they were able to do only part of the domestic activities, others expressed that they could not do anything. The need for assistance in domestic life activities was expressed by the participants as illustrated by the following quote:

"... I can cook, but I cannot get water myself and I cannot get food from the kitchen. When I am cooking, I call someone to come and help me" (P9).

Some participants revealed that they could not do any part of their domestic activities. For example, a participant said:

"... Oh, I cannot do anything with my hands ... when others have gone to work, I try to see if I can clean the house, but it is very hard ... I cannot do it (expressed with emotion) (P4)"!

Participation restrictions

As domains of participation restrictions, the participants' expressions were related to three main themes which are the inability to return to previous occupation, decreased social interactions, and inability to participate in religious activities.

Inability to return to previous occupation

Participants reported that they were not able to return to their previous occupations as illustrated by the following quotes:

"... I was a cultivator and I used to work in my fields and my children were helping me, and now they are working alone... I cannot do anything" (P5).

"... I am always at home ... I am not able to go to cultivate as before getting sick ..." (P3).

As a consequence of being unable to perform the income generating activities, the participants expressed their concern related to economical dependence as illustrated below:

"... You understand, now I cannot get money and I am being fed like a child (expressed with great emotion)" (P3).

"... Before I got sick I was a carpenter, now I cannot do it to get money, and I get what I need from my children" (P7).

While other interview participants cited their inability to return to their previous income generating activities, the participant who was a student before stroke expressed the challenge of not being able to further pursue studies as quoted below.

"I was in 3rd year of my secondary school studies. After I got sick, I stopped studying, and I don't know if I will go back to school again" (P1).

Decreased social interactions

The participants described the decreased social interactions when probed to tell if there was any change in their social relationships. Sub-themes related to decreased social interactions as felt by the participants included not being able to get out of the house, and being separated from the family and neighbors after leaving their homes for rehabilitation. For example, a participant who was not able to walk remarked:

"... I cannot reach where others are. I visit nobody. You understand it's very hard. I just sit in the house till somebody comes to see me" (P9).

Also, some participants experienced the decreased social contact because they changed residences after having stroke, and this resulted in changes in their usual social relationships as described by the participants:

"... Now, I have moved from home to stay near the hospital to continue physiotherapy. It is difficult for my neighbors to come to visit me" (P8).

"My children come sometimes from home to visit me where I stay ... but they do not come always. It is very far; it is about one hour driving" (P5).

Inability to participate in religious activities

Participants expressed their concern of not being able to participate in religious activities, and the issues related to this as remarked by the participants were inability to walk and the pain associated with walking for those who were able to walk, as illustrated below:

"... I am a Pentecost, but after getting sick I have never been to church to pray God because I have difficulty to walk" (P10).

"... I rarely go to church because I cannot reach there by myself ... I have lost my Christianity! Since I got sick, I went to church few times. It is only possible when my husband is there and brings me to church in a car" (P2).

"... Normally I am an Adventist, but currently I do not go to pray ... When I walk for about one hour I feel much pain requiring stopping and resting ... It is very sad that I cannot go to pray" (P6).

Discussion

The study findings will be discussed under two sections which are activity limitations and participation restrictions experienced with reference to relevant literature and the context of the study setting.

Activity limitations experienced

The limitations in walking as expressed by the participants were also reported in similar studies. Twenty to twenty-five percent of all stroke survivors are unable to walk without full physical assistance²². Participants in a qualitative patient-centred study conducted in South Africa also reported decreased ability to walk independently among the challenges experienced post-stroke²³. The inability to walk among the participants is not surprising given the stroke event which is commonly associated with weakness or paralysis in the legs, or problems with balance. Additionally, some characteristics of the living area of the participants such as mountains, uneven grounds or stones could be barriers for those who could walk independently. Independent walking is often used as an indicator of functional recovery in stroke²⁴,

and limitations in walking would cause other musculo-skeletal complications as well as further dependence in the activities of daily living and social isolation⁶. For instance being unable to walk would be a barrier to return to work, or to participate in different social events. The study findings therefore suggest the rehabilitation strategies aiming to improve the ability to walk among the study population.

When asked to describe the troublesome effects of the stroke, most of the feelings that spontaneously emerged in participants' interviews were related to dependence in self-care activities.

The interview results were consistent with the results from a similar studies conducted in the South Africa, in which the participants expressed limitations in self-care activities including bathing, dressing, and eating difficulties^{7,25}.

Being psychologically affected by the dependence in self-care activities was also found in another qualitative study carried out in Australia employing focus group discussions⁵. In longer term, the dependence in self-care activities could lead to emotional challenges including depression, anger, suicidal thoughts and a sense of loss³. The present study findings suggest the need of rehabilitation strategies like occupational therapy to help the stroke patients achieving dependence in self-care activities. In addition, support services to deal with the psychological problems associated with dependence are recommended.

The limitations in domestic life activities as reported by the participants were also found in other studies^{5,26}. Pound et al. found that a frequent cause of disadvantage to people with stroke is the inability to do housework activities²⁶. A study conducted in South Africa revealed that people with stroke have limitations in acquisition of necessities and caring for household objects²³. Consequently, the limitations in domestic life activities could cause emotional problems such as depression and anger³. From the participants' expressions, one of the roles of professionals involved in stroke rehabilitation is to improve the ability to do domestic activities.

Participation restrictions experienced

The inability to return to previous occupation as a challenge experienced by stroke patients was also found in other various studies. For instance, a study conducted in South Africa by Rouillard et al. exploring functioning at 6 months post stroke following discharge from in-

patient rehabilitation showed that the participants were not able to participate in all usual roles⁷. The challenge of inability to return to previous occupation could be associated with the inability to walk. According to Vestling et al., being unable to walk independently after stroke is a barrier to return to work²⁷. To go in farms for cultivating, one must be able to walk and reach there. However, during the interviews, the participants expressed that they had difficulty to move out of their homes. The majority (60%) of the participants were cultivators, and a disability clearly impacts on an individual's ability to do agricultural work²⁸.

The consequent economic dependence described by participants is consistent with the findings from the focus group discussions conducted in Ruhengeri and Gisenyi provinces of Rwanda²⁸. It was revealed that many persons with disabilities rely on gifts from friends and family. Considering the young age of the interview participants (the mean age of the sample was 56.3), which is below the pensionable age and falling into the economically active group of the population, the inability to perform usual social roles is more than individual. It is a major socio-economic issue because young patients are more often caring for dependants, and rely on work-related income²⁹. The inability to return to previous occupation frequently leads to emotional and financial hardships for stroke survivors and their families. It was highlighted that complications including stress in the family, return to previous occupation and many future needs in a population affected by stroke at young age should be considered in rehabilitation planning for stroke patients. This would be in agreement with the recommendations by the United Nations which states that in both rural and urban areas, persons with disabilities must have equal opportunities for productive and gainful employment in the labor market³⁰.

The decreased social interactions reported by the participants were also noted in many previous studies. Similar studies conducted in South Africa and Nigeria revealed that the majority of stroke patients are unable to participate in social and leisure activities^{7,31}. Relationships are perceived to be important, not only for comfort and support, but also for maintaining a sense of continuity². The decreased social interactions experienced by the participants would have a negative impact on social support networks, while these networks have a positive influence on a stroke patient's functional and psychoso-

cial recovery². With regard to the feelings of decreased social interactions, there is a need of community based or outreach rehabilitation services such as the community health centers, day programmes or home visits for stroke rehabilitation in Rwanda.

Loss of participation in religious activities was also reported in a study conducted in the United Kingdom⁸. This is most likely a consequence of difficulty in walking as discussed earlier. While the participants expressed their difficulties to attend religious activities in churches, it was reported that prayer, religious beliefs and involvement with church communities provide some stroke patients with a sense of perspective about their disease as well as providing social support³. The current study population which is psychologically affected by the stroke itself, the dependence in activities of daily living, and the social isolation may therefore develop more anxiety and depression which could be prevented by having an opportunity to take part in church activities³². Therefore, the study findings suggest that there is need for specific rehabilitation programmes to address the factors limiting the participation in various social activities by the stroke survivors.

Although the present study provides useful information that can guide clinicians and policy makers in developing the rehabilitation strategies for people with stroke, the individuals with communication or cognition problems were excluded from the interview sample. Therefore, the qualitative sample may only represent a group of individuals while the excluded group might have different experiences. Hence, future study design should consider having a more representative sample. Furthermore, the study participants were selected from only one out of 30 districts of Rwanda, and consequently the results cannot be generalized for the whole country. Future similar studies should be extended to cover the whole country.

Finally, future data analysis should consider the member check strategy to better assess the credibility of the data interpretation.

Conclusion

The study findings revealed that after the discharge from the hospital to their homes, stroke patients experience various activity limitations and participation restrictions including the limitations in walking, limitations in self-care activities, limitations in domestic life

activities, inability to return to previous occupation, decreased social interactions, and inability to participate in religious activities. Greater understanding of the impact of stroke on activity and participation is important to facilitate planning appropriate rehabilitation services in order to improve the functional status of people with stroke.

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